

Caregiver Resilience in Complex, Chronic Care

Thesis

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By

Katherine A. Simpson

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Thesis Committee:

Dr. Holly Dabelko-Schoeny

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Abstract

The purpose of this study is to examine how primary caregivers who provide complex, chronic care develop individual resilience through the exploration of the caregiver experience. As the population in the United States ages, increasing numbers of family members will serve as the primary caregiver for a family member who requires complex, chronic care. This level of care includes the performance of complex medical or nursing tasks, such as administering medication and wound care, often without professional training and oversight. Family caregivers are most often spousal caregivers over the age of 65 years, or adult children with a median age of 54 years. These caregivers have few opportunities for respite and formal support. In order to examine the development of individual resilience in caregivers providing complex, chronic care, semi-structured in-person qualitative interviews were conducted with three (N=3) caregivers referred from local healthcare facilities and support centers. These interviews indicate that resilience is represented by a duality in which the caregivers recognize and define resilience in others, but do not apply that definition to themselves, though they demonstrated the characteristics of their definition. This duality was present as caregivers considered their relationships with self and others, as their realities were not congruent with their desires. While the presence and development of resilience is a critical protective factor for caregivers, there is still a strong need for more advanced formal support and respite efforts, which is an area for further research and study in this area.

Dedication

This study is dedicated to the participants who shared their stories and made this research possible.

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Curriculum Vitae

2013.....Upper Arlington High School

2017.....B.S. Social Work, Honors with Research Distinction
Magna cum laude, The Ohio State University

Fields of Study

Major Field: Social Work

Minor Field: Health and Society

Table of Contents

Abstract.....	iii
Dedication.....	iv
Acknowledgments.....	v
Curriculum Vitae.....	vi
Chapter 1: Statement of Research Topic.....	1
Chapter 2: Literature Review.....	3
Chapter 3: Methodology.....	10
Chapter 4: Results.....	15
Chapter 5: Discussion.....	25
References.....	31
Appendices.....	34

Chapter 1: Statement of Research Topic

As the population in the United States (U.S.) ages, increasing numbers of family members are in the position to serve as the primary caregiver for a family member who requires complex, chronic care. Complex, chronic care is defined as caregiving that includes the performance of complex, medical or nursing tasks (Reinhard, Levine, & Samis, 2014; Reinhard, Levine, & Samis, 2012). According to Reinhard, Levine, and Samis, (2014) family caregiving today is largely an issue affecting adult children and spouses of the care recipient, with nearly one in five spouses serving as a primary caregiver. Within this population, half of all spousal caregivers are women, and on average, spousal caregivers are over the age of 65 years (Reinhard, Levine, & Samis, 2014). Of non-spousal caregivers, 81 percent are either a female adult child or other relative, with a median age of 54 years (Reinhard, Levine, & Samis, 2014).

Additionally, nearly half of family caregivers report performing medical or nursing tasks for care recipients that are traditionally performed by skilled professionals in medical facilities, such as medication management and delivery, operating medical equipment, and providing wound care, with limited training and oversight (Reinhard, Levine, & Samis, 2012; Reinhard, Levine, & Samis, 2014). These medical and nursing tasks are often in addition to assisting with daily living activities, such as bathing, dressing, and eating, and instrumental activities of daily living, such as shopping, managing personal finances, and arranging for outside resources (Reinhard, Levine, & Samis, 2012; Reinhard, Levine, & Samis, 2014).

As a result of both the medical and lifestyle chores a caregiver is responsible for, many caregivers experience high levels of stress, which contributes to relatively poorer physical and mental health when compared to non-caregivers (Lu and Wykle, 2007; Reinhard, Levine, & Samis, 2014). This stress, according to Reinhard, Levine, & Samis (2014), is often a response to

a lack of a personal locus of control in the decision to become a caregiver, a lack of perceived personal time, and struggles in balancing responsibilities. Consequently, these responsibilities leave many caregivers little time for personal care, such as maintaining healthy nutritional habits and exercising, which may contribute to sleep disturbances, fatigue, anxiety, depression, worry, and loneliness (Bevans & Sternberg, 2012). In cases in which the caregiver is providing complex, chronic care for an extended period of time, the high levels of stress may also lead to hormonal imbalances and cortisol levels that impact the heart, brain, immune system, and respiratory tract (Bevans & Sternberg, 2012).

The purpose of the study is to examine how caregivers who provide complex, chronic care as the primary caregiver develop individual resilience by exploring how caregivers define resilience, their personal experiences regarding caregiving, and the caregivers' beliefs regarding their personal resilience. This study is not intended to create an exhaustive examination of the development of caregiver resilience, but is designed to create a basic understanding of how caregivers develop resilience, and ways in which research can further this discussion.

Chapter 2: Literature Review

Understanding how caregivers who provide complex, chronic care develop resilience first requires a review of the available literature on resilience, caregiving for individuals with complex and chronic illnesses, caregiver burden and resilience, and potential mitigating and respite factors for caregivers. Resilience, as defined by the Oxford Dictionary, is the “capacity to recover from difficulties; toughness” and “the ability of a substance or object to spring back into shape; elasticity” (2017). Despite its technical accuracy, this definition of resilience reflects a quality that is predominantly utilized during a period of recovery or after an event (Robertson, Cooper, 2013). A more expanded definition of resilience includes a perspective that reflects the ongoing protective capability that enables “not only reactive recovery but also proactive learning and growth through conquering challenges” (Youssef & Luthans, 2007; Robertson & Cooper, 2013). Then again, these definitions can be broken down into psychological and behavioral components, as psychological resilience focuses on the ability of an individual to sustain their mental health and well-being throughout adversity while behavioral resilience focuses on an individual’s capacity to remain functionally effective throughout times of difficulty (Robertson & Cooper, 2013; Limardi et. al, 2015).

Though multiple definitions and definitional components to resilience exist, personal resilience is often broken down into adaptability, confidence, social support and purposefulness, which may include traits centered on optimism, active coping, cognitive flexibility, and physical exercise. These traits can predispose individuals to better manage adverse situations in the future, as stable personality characteristics have been linked to resilience levels, however, intense negative experiences have also been shown to decrease individual resilience for subsequent, traumatic situations (Robertson & Cooper, 2013; Khoshaba & Maddi, 1999; Cicchetti, 2010;

Furnham, Crump, & Whelan, 1997). From the available literature, it is clear that the concept of resilience is not easily defined, particularly as it relates to the caregiver experience and as it is influenced by previous experiences and perceptions. As a result, it is critical to create a functional working definition of resilience that is broad in nature, and encompasses each definitional component and that is based on the perspectives of caregivers. Without the caregiver perspective, the definition of resilience has the potential to exclude important factors that reflect both the development and sustainability of caregiver resilience.

Within the scope of caregiving, caregiving for a complex and chronic illness includes the performance of complex, medical or nursing tasks (Reinhard, Levine, & Samis, 2014; Reinhard, Levine, & Samis, 2012). These tasks may include administering medication, wound care management, operating medical equipment, and are frequently completed with limited oversight from trained, healthcare professionals. As a result of the additional burden caregivers face when providing complex, chronic care, these experiences must be examined as the focus rather than caregiver experiences with more traditional caregiving. Caregivers providing complex, chronic care frequently face the burden of managing both their own self-care with the needs of the individual they care for. Time spent on care for the care-recipient usually requires approximately 20 hours per week, but is sometimes as high as 40 in instances of severity illness and complex care (Parks & Pilisuk, 1991; Aldeman et. al, 2014). The average time spend completing caregiver tasks varies greatly for each individual and the level of care needed for the care recipient, but typical activities include physical tasks, such as medication, hygiene, household chores, transportation, and time spent at healthcare appointments. In addition to the tasks specific to the care-recipient, many caregivers must also balance the burden of their own needs, including employment, respite and self-care, financial management, and social responsibilities (Parks &

Pilisuk, 1991). As the need for care increases, caregivers often sacrifice their personal needs for the needs of the care-recipient and spend more time during the day providing care for another. This time is exacerbated by other concurrent factors and responsibilities that frequently cannot be decreased in order to spend more time as a caregiver. These responsibilities may include time spent caring for children or other individuals needing care and time spent at employment positions.

As a result of the high level of care needed in instances of complex, chronic caregiving, caregiver burden often results in burnout. According to Sautter et al. (2014), caregiver stress and burden is frequently exhibited first in the early stages of caregiving, and then typically remains at a constant level throughout the caregiving experience. As a result, many caregivers do not receive support from medical institutions because of a lack of focus on the caregiver within the medical scope of practice. This oversight is strongly correlated with negative effects of stress and caregiver burden, and is not addressed until the affects are severe and overwhelming as caregivers downplay the severity of their needs to protect the care-recipient (Sautter et al., 2014; Bevans & Sternberg, 2012; Parks & Pilisuk, 1991). Many caregivers become physically and emotionally exhausted as their lives become increasingly disrupted. Emotional consequences for caregivers can include anger, guilt, impatience, loss of self, and chronic stress with anticipatory bereavement, as caregivers balance the internal and external expectations placed upon them (Limardi et. al, 2015; Parks & Pilisuk, 1991; Bevans & Sternberg, 2012).

Furthermore, Alden (2003) describes the symptoms of caregiver burnout, such as irritability, ongoing depression, chronic fatigue, irregular sleep patterns, and a lack of self-identity that is seen in either neglect of the care receiver, or an inability to separate the needs of the caregiver from the care receiver. While recommendations to cope and prevent symptoms of

caregiver burnout can be mitigated through self-care and receiving external help, caregivers are unlikely to pursue available options. As caregiver stress becomes more overwhelming, the chance a caregiver will practice the self-care suggestions decreases. This decrease strongly lessens the probability a caregiver will seek out aid for his or her own purposes (Lu & Wykle, 2007; Alden, 2003; Bevens & Sternberg, 2012).

Despite the prevalence of caregiver stress and burnout, many caregivers demonstrate remarkable resilience against the negative effects of caregiving. In a case study by Olsen (2003), a spousal caregiver was able to remain positive and mediate the effects of caregiver stress and burnout by utilizing a variety of organizational techniques, faith-based practices, and by working to find the joy in the midst of the care receiver's illness. Furthermore, Freedman, Cornman, & Carr (2014), found that female spousal caregivers reported greater levels of happiness from providing care than from performing household chores. Additionally, Clark (2002) found that both individual and family levels of hardiness related to lower rates of depression and fatigue in caregivers, which may be a result of more efficient coping techniques, help seeking, and social support. Though there is available evidence that supports the potential benefits of direct caregiving, more research is needed in order to determine how these benefits develop and if caregiver resilience can be associated with these benefits. By determining how resilience affects the individual caregiver, further research can be developed to increase the development of individual resilience in primary caregivers.

Though the burden of providing complex, chronic care has been linked to both positive and negative effects on caregivers, it is critical that measures are taken to mitigate the negative effects and provide respite for caregivers. Because caregiver burnout is often connected to internal and external expectations, it is critical that the caregiver is provided with education

about the care recipient's illness and needs. This education can be delivered through supportive trainings that address care techniques, like equipment management, training that focuses on self-care and self-preservation, and through counseling practices that discuss caregiver stress, coping mechanisms, and ameliorative strategies. Throughout these strategies, caregivers should be encouraged to improve their self-care practices and to maintain their health, as caregivers frequently neglect their own health and wellness in terms of preventative and managed care. Additionally, caregivers should be encouraged and treated as a central part of the care team. During visits, physicians should address the caregiver as a valuable asset to the treatment process and should address the caregiver's needs and concerns during each visit. Furthermore, treatments should account for the needs of both the caregiver and the care recipient in order to maintain a balance in the caregiving process, and to ensure technology is being utilized as a measure of support (Aldeman et al, 2014; Bevans & Sternberg, 2012).

Considerable efforts should also be made to link caregivers to respite care programs and assistive services, such as home health care programs, non-medical home care services, legal and financial counseling services, web-based resources, and support groups for both the caregiver and care recipient. Through these respite services, the burden of care on the caregiver is reduced, and caregivers may feel more equipped to manage their personal health and provide higher levels of care for the care recipient (Aldeman et al, 2014; Bevans & Sternberg, 2012). By working towards mitigating the effects of caregiver burden and connecting caregivers to support resources, caregivers may experience higher health outcomes that are reflecting in increases in resilience and decreases in negative psychological, behavioral, and physiological effects for the caregivers (Bevans & Sternberg, 2012)

Although caregiving has the potential for widespread and negative consequences for caregivers, the development and support of resilience in caregivers providing complex, chronic care through interventions can provide positive outcomes for caregivers. One of the most critical interventions and pathways to further interventions is the process of completing a caregiver assessment. This assessment gathers information about the caregiving situation and addresses specific issues, needs, strengths and resources, the physiological and emotional capacity of the caregiver, the caregivers ability to meet the needs of the care recipient, and assess the caregiver's interactions and relationships with health care teams (National Academies of Sciences, 2016). Through the utilization of an assessment, caregivers can be evaluated for eligibility for services, how to appropriately provide services and skill-building assistance, and to determine the overall wellbeing of the caregiver. Additionally, because caregiver assessments are not considered a part in traditional health delivery settings, the use of a caregiver assessment allows the health care provider to tailor suggested services to the needs of each individual caregiver, which creates an opportunity for more specialized support services (National Academies of Sciences, 2016).

Following the initial assessment interventions, more structured interventions should be made available to caregivers. Some of the most effective interventions include individual therapy or counseling, such as the COPE Intervention, to target multiple facets of caregiving, and have had marked success in reducing caregiver burden, reducing institutionalization rates of the care recipient, and managing the symptomatology of the care recipient (The National Academies of Sciences, 2016). Though these therapeutic interventions do not reduce the specific care needed by the care recipient, they have shown reductions in caregiver burden, depressive symptoms, and have also shown increases in the self-help behaviors, social support, and feelings of personal efficacy and confidence in caregivers (National Academies of Sciences, 2016).

Community and group based interventions are also beneficial for caregivers. Programs, such as Home-Based Supportive Services that provide financial assistance to reduce family care expenses, have shown increased mental health outcomes, access to health care, and improved self-efficacy in caregivers. Family-based interventions that focus on providing psychoeducation have shown reductions in negative reactions to behavioral symptoms of the care recipient by the caregiver (National Academies of Sciences, 2016). Furthermore, by utilizing resources already available within a community, including places of worship, libraries, community centers, and schools, more emotional and logistical supports may become available to caregivers. These community supports may also serve to recruit additional caregivers who are not working within the system already, and would increase the scope of caregiver support and improvement. Community-based programs like the REACH Program, for example, increase caregiver empowerment and resilience, and encourage caregivers to reclaim their identities as an individual while still acting as a caregiver (National Academies of Sciences, 2016).

By utilizing interventions that focus on assessments and individual and community-based programs, caregiver resilience may be increased as they are supported and educated about their work as a caregiver. From these interventions, it is clear that the caregiver experience is central to the care process and should be identified by the health care practitioner to create a positive caregiving experience by linking caregivers to individual and community-based intervention and support services.

Chapter 3: Methodology

Theoretical and Conceptual Framework

This study is influenced by the phenomenology methodology within qualitative research. This study is guided by phenomenology, because though the caregiving experience is not a single moment, it can be generalized to a single experience within caregiving. Through phenomenology, the caregiver's experiences become their reality and therefore influence their resilience through their perceptions of their own reality. Additionally, by examining caregiving resilience through their intentionality of consciousness, the focus of the individual caregiver becomes the standard that guides and influences the research. This study also represents the basic tenets of grounded theory, as it may aid in developing new theories regarding the development of caregiver resilience, but this study will not reach the depth and level of saturation required for grounded theory research (Schutt, 2001).

Research Design

In order to determine how caregivers develop resilience in complex, chronic care situations, in-person interviews were conducted with three caregivers (N=3). Each participant was a familial caregiver who was caring for someone with cancer. These participants were asked to explore eight questions designed to develop a deeper understanding of how individual caregivers develop resilience. The first question focused on how the individual came to serve as a primary caregiver, including what the participant's daily life looks like when providing complex, chronic care, and if the primary caregiver receives aid from other caregiving sources. By asking this question first, the background narrative of the caregiver was developed, which clarified if the caregiver had already developed a high level of individual resilience before becoming a caregiver, or if the caregiving role was a direct factor in the participant's resilience.

The second question focused on the caregiver's individual interpretation of what resilience is, and what components contribute to resilience. Discovering how a caregiver defines resilience in his or her own situation creates guidance for creating a definition within the study, and for evaluating outcomes.

The third question discussed what the caregiver finds to be the most challenging aspect to providing complex, chronic care, and will be followed up by how the caregiver handled that challenge. This question also developed further understanding of what resiliency looks like and feels like to the participant. Through discussing how the caregiver handles challenging tasks in their role as caregiver, the personal skills and coping mechanisms utilized by the caregiver may become evident and inform how the caregiver develops resilience through these mechanisms. The fourth question explored if the caregiver felt supported in their role, and if there are factors that relieve any tension or stress from the caregiver's role. By discussing potential factors and social supports available to the caregiver, it may be possible to determine if these factors aid in the development of caregiver resilience, or if the caregiver developed resilience as a result of the absence of social supports and factors. The final question addressed what, if anything, the caregiver would want others to know about the role of a primary caregiver in a complex, chronic care situation. Through this discussion, further research into caregiving may be influenced as knowledge is developed. Additionally, this may aid to further explore how the caregiver is supported, and to what extent the caregiver is impacted by their role.

Sample

A total of three participants were recruited for this in-depth, semi-structured and exploratory qualitative study. While this is a relatively small number compared to other studies, the nature of this study required open-ended interviews to explore the individual experience of

participant in developing personal resilience to the burden of their role as a primary caregiver. Therefore, the number of participants involved must remain low in order to gain a large amount of information from each interview that is unique to each individual. In addition, caregivers in general, and caregivers for individuals with complex and chronic care needs in particular, are difficult to recruit for scientific studies because of the demand of their caregiving activities. No respite for the care recipient was provided during interviews due to cost and feasibility.

Specific exclusion and inclusion criteria were employed to select participants. Potential participants must currently be the primary caregiver for another individual who is suffering from a chronic disease, such as Alzheimer's, Dementia, or for cancer and other disabilities that require care for a period exceeding six months. Additionally, the care provided for the individual must be complex, which includes performing medical or nursing tasks without formal, professional training, administering or managing injections, medicine, or intravenous fluids, and performing wound care. Potential participants must also be over the age of 18 and self-identify as resilient, but may be a family or non-family caregiver as long as they are the primary caregiver without formal or professional training and do not receive monetary compensation for their care. Additionally, participants must also speak English fluently, but may come from any religious, socioeconomic, racial, or ethnic backgrounds.

Measurement and Instrumentation

The primary constructs of interest in this study address the development and perception of participants regarding resilience in their role as a primary, complex, chronic caregiver. These primary constructs include the participant's experience with caregiving, their personal definition of resiliency, what resiliency looks like and feels like to the participant, what the interviewee perceives as challenges to behaving in a resilient way, and what they consider to be their

supports for being resilient. By analyzing the interviews for these primary constructs, the ways in which the participants feel, think, and behave regarding resilience can be determined. As a result of the qualitative and open-ended nature of this study, the semi-structured interview technique will allow the participants to discuss relevant information.

Study Process

Participants were recruited from the Mount Carmel West Oncology Center and the Cancer Support Community in Columbus, Ohio. Recruitment was completed both in-person, and through electronic communications with potential participants. Additionally, the recruitment process included semi-structured interviews in order to determine if potential participants match the inclusion criteria. In order to retain participants, \$25 Visa gift cards were given to each individual who agreed to participate in the study, and were given to the participant directly before the interview is conducted.

The interview process followed recruitment, and was conducted in-person for each participant. The interview location was chosen by the participants, and took place within a home environment, and two public places. Each location was safe and comfortable for the participant, and maintained a low-level of noise interference to facilitate clear interviews and transcriptions. During the interview, the primary researcher explained the study process and received informed consent from the participant. The primary researcher then conducted the interview, following the interview guide and asked additional questions for clarification and responded to facilitate open communication from the participant. Each interview was recorded and transcribed by a professional transcription company. Following the completion of the transcriptions, each interview was coded separately by the primary and co-researcher to support the reliability and validity of the analysis. Specifically, the information gathered in the interviews was coded for

overarching themes and definitions were created based on common words and phrases used to create a single analysis for each individual interview. In order to maintain validity and reliability, the measurement coding process was completed by two independent researchers, who will compare findings throughout the process in order to check for bias and accuracy. Researchers were in 83% agreement about themes and definitions. In instances of disagreement, researchers discussed reasoning and edited definitions for congruency to create the final themes.

Chapter 4: Results

The purpose of this study was to examine how primary caregivers who provide complex, chronic care develop individual resilience by exploring how caregivers define resilience, their personal experiences regarding caregiving, and the caregivers' beliefs regarding their personal resilience. The purpose was not to create an exhaustive examination of the development of caregiver resilience and the ways in which caregivers perceive resilience, but was designed to create a basic understanding of how caregivers develop resilience. Through the examination of the development and perceptions of caregiver resilience, recommendations for further study, programming, and an examination of gaps in the results will be discussed.

The results of this study provide a detailed glimpse into the lives of the caregivers interviewed, and provide foundation understanding to use in further examination of the issue of resilience development among caregivers. The caregivers interviewed for this study were all female, spousal or familial caregivers caring for their husband, their mother, or both. Each caregiver was providing complex, chronic care for a care recipient with a terminal cancer diagnosis. One of the primary results of this study was an understanding of the role resilience plays in complex, chronic caregiving and how the caregivers perceived resilience in regards to themselves and others. Under the overarching theme of resilience, the results were divided thematically into categories centering on the caregivers' experiences. These thematic categories are the caregivers' experience as an individual within the caregiving situation, the caregivers' relationship with the care recipient and with the disease, and the caregivers' relationship with others. Within these more encompassing thematic categories, both the caregivers' experience as an individual and the caregivers' relationship with others were further divided in order to

examine the additional theme of the duality of reality and desired reality within the caregiving experience. These themes are illustrated in the Table 1 below.

Table 1. Identified Themes

Resilience – (<i>Caregivers behaved in this way, but did not see themselves in this way</i>) Strength; Faith; A person who keeps going in the face of adversity, bounces back from troubles, accepts reality and moves on		
Caregiver and Care Recipient Relationship and Disease	Caregiver as an Individual	Caregiver's Relationship with Others
<ul style="list-style-type: none"> • “[Understanding the terminal nature of his cancer] was a big burden on me for a long time until we finally came to terms with the fact [he] wasn’t going to be [ok] – it took him time.” • “Sometimes I feel like he’s draining every bit of life out of me” 	Reality: “I’m exhausted all the time” “Sometimes I feel like I’m going crazy” “I get very depressed”	Reality: “[In the beginning] I thought that we were all gonna be in it together...It didn’t turn out that way... That disappoints me.”
	Desire: “I can take a bath. Oh, my God I’m dying for a big bubble bath... I’ve taken showers for years... I miss my baths”	Desire: “If we could have an in-home nurse... taking care of [the house]. Just to have him be my husband and not [a] patient”

The results of this study were centered on the primary caregiver and their experiences in order to examine how their perceptions and experiences were impacted by the idea of resilience. As a result of this focus and from the information gathered through the interview process, the theme of resilience is the primary theme through which each sub-theme is viewed. By using resilience as the primary theme, a strong working definition was created through the interview process by the caregivers. The working definition of resilience as stated by the caregivers is: strength; faith; a person who keeps going in the face of adversity, bounces back from troubles, accepts reality and moves on. Though the caregivers in this study created this definition, it was used almost exclusively to describe others, as the caregivers did not apply their own definition of

resilience to themselves and their experiences. Rather, their resilience largely came from external sources that, while unique to each individual caregiver, were not internal. This congruence is demonstrated throughout the entirety of the data collected. Examples of this are provided as direct quotes from the data.

Resilience Definitions:

Participant 1: Well, when you say resilience, I think of the word as strength. Being able to put up with something for a long time...dealing with something that never appears to get resolved, or it's just so ongoing all the time that it never gets any better

Participant 2: Person who keeps going into the face of adversity, bounces back from troubles, accepts what is and moves on.

Participant 3: Faith

Resilience and Self Perceptions:

Honestly, I don't think [that I am resilient]. I get very depressed and sad sometimes. I don't like to be that way. I would like to be more positive, but I'm more of a realistic person... I think I come from a long line of people that work hard and don't give up. That's gotta be what it is. It's probably from my family, an inner strength. I think some of it is probably because I'm taking care of people (Participant 1).

[My resilience comes from my husband]. My husband [is] almost non-human in his ability to deal with pain, his ability to have a positive attitude no matter what... It was hard to be a physician and to see that initial CAT Scan to know we're screwed from day one. [My husband] is gonna die, and I know this (Participant 2).

My faith, my belief system. I would probably have to say, most importantly is, in order to stay strong, and now show displeasure or frustration. [Caregiving] has stretched my faith and my patience (Participant 2)

From the duality of the definition and the perception of how that definition fits the individual caregiver within the theme of resilience, the sub-themes of the caregivers' experience are apparent. These sub-themes focus on the caregiver and their experiences as an individual in order to accurately portray the caregiver separately within the care situation. The sub-theme of the caregiver as an individual is also represented in a duality that contrasts the caregivers

experience with their desired experience as a caregiver. The caregivers reality is defined by tasks or experiences described by the caregivers that occur within their identity as an individual, such as balancing responsibilities and maintaining external responsibilities, self-care practices, a loss of self, a focus on faith practices, and the caregivers' sense of control. The caregivers desire is defined by tasks or experiences the caregivers hoped for, fantasized about, or mentioned as a positive alternative to their current situation as a caregiver. By examining smaller themes within the individual experience a larger, more comprehensive definition and examination of the caregiver experience was possible. Illustrative quotes from the data below demonstrate the reality of the caregivers' experiences and the contrast with the desires of the caregivers.

Caregiver Reality:

I was laid off from my job...I was living off my severance [when my husband was diagnosed]. Basically, now I'm on unemployment so I'm at home... I need to get to the library and do stuff because I'm also looking for a job. I put in applications, but I'm not hearing everything because it needs to be around specific hours (Participant 1).

It's mainly me [providing care], and sometimes I feel like I'm going crazy, and then I kinda recoup, and then I get back on the saddle because you gotta do it (Participant 1).

I'd like to go sit somewhere in a closet and cry... [Caregiving is like] if you have a job and you have no days off to decompress... Sometimes I feel like I'm the kid who's trying to hid from the parents, you know, find a little cubbyhole somewhere... I'll have ten minutes in the car by myself without anybody asking me any questions or asking me to do something for them. Or I'll go to the bathroom and see how long I can be in there without being questioned or asked something (Participant 1).

In order for me to make it through the day, I don't turn to alcohol. I don't turn to drugs. I do love food, which is probably my worst thing (Participant 1).

The hardest times have been when [my husband] can't sleep. I can do almost anything. I'm pretty strong if I can sleep. Even despite huge stress, I can sleep. I'm not a person who loses sleep when I'm stressed. I eat when I'm stressed. I've gained 50 pounds, by the way, in this last year and a half... That's been the times when I've really fallen apart when we had three or four days where he is in pain at night and walking the floors and moaning and crying in pain. Then I go several nights [without sleep] and for the most part [I'm] still working (Participant 2).

I don't complain because I'm scared to... I'm not even crying, I don't allow that... [I have to] meet all the expectations, and [I'm] scared to make a mistake (Participant 3)

It may not seem normal, but I just pound the pavement... I schedule her – paying the bills, her bank, her doctors, her therapy, her Coumadin clinic, and then the same way with him, and then take her to the doctor, to the grocery stores and get her what she wants. The same way with my house, and to its – its a full time job all day, every day, all night, every night (Participant 3).

Caregiver Desires:

I like working to help other people. I wanna have some type of – I wanna give back some sort so I have satisfaction I my life (Participant 1).

Oh, my God, I'm dying for a big bubble bath... wouldn't I just love it if I went to a hotel with a big bathtub just like for three days just by myself... If I could get some breaks, maybe I wouldn't be so frazzled all the time... I would be able to fill my cup and be able to be better instead of always being frazzled. I think the hardest thing is taking time for myself... I think I would feel better if I just had a little break (Participant 1).

I was feeling like I need to do something to take care of myself (Participant 2).

I've yet to have one phone call from [anyone] just to see how she's doing... 'Hey, man, I need a break,' you know, but it's all good. I don't know why I'm upset, but probably because I haven't thought about this stuff in a while (Participant 3).

Father God is still in control...when He's had enough, we're all gonna know it and that, I'm waiting for that day (Participant 3).

The second sub-theme focuses on the caregivers' relationship with the care recipient and their disease. This theme examines how the caregivers' relationship with the care recipient has changed during the process of providing care, as a result of both personal changes of the care recipient and external, lifestyle changes that have occurred. Through this lens, ideas of anticipatory loss, direct examples of the caregiving burden, perceived helplessness, and the caregiver's sense of control become evident. This sub-theme also was strongly influenced by the caregivers' love or affection for the care recipient as a consistent theme from each participant. Unlike the caregivers' experience as an individual, the duality of reality and desire was not seen

in the data for the caregivers' relationship with the care recipient and the disease. Examples of the caregivers' relationship with the care recipient and the disease are included below.

Caregivers' Relationship with Care Recipient and Disease:

When he first came home he was really difficult... he would refuse certain things. It was very difficult to take care of him because he wanted to do – he wanted to be in control of everything, and obviously, he can't do what he thinks he can do... In his mind, I think he thinks I'm trying to control him and I kept trying to explain to him that I'm trying to protect him. He doesn't see it like that. Brain injuries are very, very weird and I think that his personality is different now. He's short tempered. He can be aggressive, very demanding, wants everything right then. It's affecting both me and our son (Participant 1).

He just bought that new truck, 2016 in January. We own the two cars there and he didn't want me to get rid of the new truck. I don't know what's going to happen. His life expectancy is 14 months...[My husband] can't drive, so anywhere he wants to go, and sometimes we argue because he comes up with these impulsive, insane ideas that are just time killers when I could be doing something else (Participant 1).

[He] follows me around because it makes him feel better to know that I'm there with him. Sometimes he can get confused. One time I was laying in bed, and he's looking around the house for me, and I was actually in bed right next to him. He's obsessed with making sure he's with me and I'm trying to get some breathing space... He's demanding, which is difficult. He likes beck and call girl and he wants to be around me and he doesn't really like anyone else taking care of him, but me. Sometimes I feel like he's draining every bit of life out of me (Participant 1).

To want to have hope [that he could survive] with him, but to know that it's not gonna happen. It was a big burden on me for a long time until we finally came to terms with the fact that it wasn't – he wasn't going to be [ok] – it took him time (Participant 2).

Sometimes, it was frustrating for me like, okay, you need to have a couple dimensions. You can't be all masculinity and bravado. The kids need to see that this sucks sometimes every once in a while. Sometimes, it was frustrating, but truly, for the most part, his strength is what we all have lived off of (Participant 2).

My expectation is to meet their need before they need to ask for it...you would think one would know their mother enough to be able to see what they need before they have to ask for it. When somebody has gone through what my mother's gone through...you want to give them every reason to get better, no matter what the diagnosis is. They've done all the surgery. We've done all these things. She's going no further with it. She has a very fast-growing cancer, and so, I have a lot ahead of me, yeah, and I'm not looking forward to it (Participant 3).

I have to be strong for her, and I can't let this happen, so I've got to get it together here, kid... I want my mother healed. I don't want to watch my mother waste away, and I feel that's what's happening, and I'm scared. Where [do] caregivers go for this? (Participant 3).

I guess what I would say, as the caregiver, the most important thing is to help that patient find their purpose, because their life has changed, totally drastically changed forever more... I don't need to take on another fight, so I'll just leave it alone and do the best I can. I think she's well worth that (Participant 3).

Life and death issues are not easy, and dealing with people with cancer that you know has chosen not to do anything further to extend that, that leaves a whole other layer that – as a caregiver, you have to bury them knowing, and yet, the other side of that is you're constantly looking. Is this her turn to go to Heaven? Oh, God, help me. I'm so sorry. I really am sorry. I don't want to face my mom dying...and I'm scared (Participant 3).

The final sub-theme focuses on the caregivers' relationship with other. A broad theme, this category is defined by the caregivers' relationships with both individuals, systems, and organizations that they function within, and their perceptions of these interactions and perceptions. Like the caregiver as an individual, this sub-theme is categorized by both the reality the caregiver faces and their desires. These are evident through ideas of social isolation and social support, their experiences with healthcare practitioners and the healthcare system, and external expectations from individuals other than the care recipient. This perspective is critical because it provides a holistic examination of the caregiver within their environment. Quotes from the data are provided as examples of both the reality and desire of the caregivers' relationship with others.

Caregiver Reality:

When he first got diagnosed I thought that we were all gonna be in it together, you know, like his children were gonna be a big part of it. It didn't really turn out that way...that disappoints me. Actually, it hurts me and it hurts him too...[Family and friends] don't really do anything to give me respite. I mean I usually have to cater to them like guests coming... My sister says she's very proud of me. She says pretty much everybody said that I shouldn't bring him home from rehab. They said they didn't think I could do it. I'm going it and she said she's proud of me (Participant 1).

I looked into [a home health care aide program] because we're on Medicaid and the girl they sent us wasn't very much of a go-getter 'cause I guess she was coming up off of a night shift, for a long-term night shift, and of the two times that she came, one time she was almost sleeping on the couch (Participant 1).

I have to say that our doctor, our regular doctor, we both go to the same doctor, is unsupportive (Participant 1).

I feel like if I weren't a physician, there would be more people helping me. [They say] 'Oh, you can do this because you're a physician. Oh, you know how to do that. Oh, you can just call that in'. A hospice nurse actually said that to me. 'I guess you could call that in'. I was like 'no. I am a caregiver. I'm not a doctor in this situation. I will not be calling in any medication' (Participant 2).

I had one friend who's also a very good friend and who's really been here for me, but she made a really big mistake early on. She took all of [my husband's] information from the Lotsa site and copied it and sent it to a friend of hers without asking me at all, to a friend of hers who's a cancer researcher, and then sent me this e-mail. 'This is what my friend says he should be doing'. I was livid...I was screaming angry (Participant 2).

[One resource] that has been extremely helpful to us. I think it's good for anyone surrounding cancer to be aware of, is a thing called Camp Kasem...I'm telling you, these [camp counselors] are amazing (Participant 2).

I haven't had time for friends for a long time, so, there's no outlet there, and I don't really feel like hearing their problems when I'm dealing with life and death issues with both my mom and my husband. Your life becomes about them, and that's that (Participant 3).

Didn't [doctors] take an oath to do no harm? Sometimes, you do more harm with a dirty look than you ever do with anything you say... You shouldn't be in the hospital on [November 4], and not find out until the end of December that you had MRSA, nothing as sent to us, and she'd been in the hospital two times since then, so, I was very upset about all that, and I had a right to be, because I was her caregiver (Participant 3).

It's like very little slack is given, just expectation, or disappointment, disapproval if we're late. It's hard enough being a caregiver for one, so, you are probably interviewing the wrong person. I'm taking care of two life-critical people at the same time, so there's a reason why I'm [struggling] (Participant 3).

Caregiver Desires:

I should stay with my family. The family's gonna be there. They're gonna try and find [a new home health aide]...I was hoping to get a little bit of a break (Participant 1).

I think I would feel better if I just had a little break. I mean even if his kids were to come up and take him for a day or a weekend... We go to the Vineyard [Church], but my husband isn't much of a joiner. I suppose if we had church, we would probably get some help, but my husband's private and I don't think he wants anybody in his business (Participant 1).

Gosh. If we could have an in-home nurse just living there, taking care of – but not in my space so much, but I don't know. Just to have him be a husband and not have to be like a patient (Participant 2).

Inclusion, sometimes, some caregivers I know operate feeling like they're on the outside looking in, and they have to go by way over the trail just to get a little bit of information, and if you don't have [access] it makes it a little bit difficult (Participant 3).

[Doctors] - show your people more compassion, the patients, as well as the spouses, and the caregivers. Talk to them like they matter, because they're the ones bringing your patient to you. Don't discard them... Direct [patients] into a position or a place of which they can get help, and get some direction, and maybe a clearer understanding of what's going on with them. Take [more time with patients]... I think if [healthcare practitioners] were just a little more understanding with the people around them, not just the patients, that it goes a long way. (Participant 3).

I think that the whole problem with a lot of it is that you're thrown out there...in the deep end, and you don't have any set resources of which to pull from, and you're so concerned with getting medications, and dieticians, and diets right, and household right...No doctor did that to help her, but I did (Participant 3).

Each theme within this works together to create an idea of the process and experiences included in providing complex, chronic care for an individual with a terminal illness. Within this study, the caregiver serves as the center of each theme and is the basis for the working definition of resilience and how each experience is related to the caregiving experience. From the working definition of resilience, the sub-themes of the caregiver as an individual, the caregivers' relationship with the care recipient and disease, and the caregivers' relationship with others are identified and developed. Though this is not a comprehensive study on every component of caregiving in complex, chronic care situations, it demonstrates the duality of the caregiving experience as caregivers face a reality that does not meet their expectations or hopes of what

their lives could be. However, each caregiver expressed clear desires about ways in which they hoped or wanted positive change in within their experience. Additionally, though these desires were not always directly stated, the negative realities presented can also be interpreted as a desire by identifying the positive opposite of the reality. From these results, further research and programs can be developed to examine how to decrease the gaps between the caregiver's desires and their reality in order to promote positive outcomes for the caregivers and the care recipients.

Chapter 5: Discussion

The results of this study demonstrate a distinct duality in how caregivers perceive resilience and experience their reality, and how this duality relates to their desires. From the data, it is apparent that though the caregivers clearly define resilience, it is perceived externally as the participants do not apply their definition to their work as caregivers. Additionally, the data represented the duality between the reality of the caregiver's experiences as they functioned with the care recipient and others, and their desires for these interactions. These findings strongly correlate with the available research, as it supports the experiences of resilience, caregiving for individuals with complex and chronic illnesses, caregiver burden and resilience, and the potential mitigating and respite factors for caregivers.

As defined by the Oxford Dictionary, resilience is the “capacity to recover from difficulties; toughness” and “the ability of a substance or object to spring back into shape; elasticity” (2017). When the definition of resilience is applied within a social context, it includes the ongoing protective capability that enables “not only reactive recovery but also proactive learning and growth through conquering challenges” (Youssef & Luthans, 2007; Robertson & Cooper, 2013). Through the frame of these definitions, the caregivers' definition of resilience is congruent with the existing definitions, both in their abstract and psychological components. Despite this agreement between the literature and the results, it is critical to note that the caregivers' perceptions of resilience were external only and was not applied to their experiences as caregivers. This difference conflicts with the available research on the protective factors of resilience because it introduces the need to examine the importance of perception on resilience. While each caregiver in this study exhibited large quantities of resilience from an outside

perspective, the internal perception of each participant was that they did not exhibit these qualities, which may impact the protective factors of resilience in these situations.

The results from this study were also congruent with the available literature on caregiving for complex and chronic illnesses. Participants mentioned components of caregiving including medication management and administration, and wound care, treatment, and management. Participants also discussed the burden of providing care for the care recipient for upwards of 18 hours a day, which was substantially higher than literary estimates, but showed similarities in the burdens of balancing caregiver tasks with their own needs. The higher time commitment required of caregivers in this study may be linked to the intricate situations caregivers in complex, chronic care situations face. The available literature and research frequently combines caregivers into a homogeneous group. This sub-group of caregivers who provide complex, chronic care may be unique to these caregiving situations in regards to risk factors, including hour of care. This burden is also illustrated in the difference between the caregivers' realities and desires, as they discussed the desire for more support, respite aid, and fewer external responsibilities, while finding the opposite was true in reality (Parks & Pilisuk, 1991; Aldeman et. al, 2014).

From these burdens, the experience of caregiver burnout and stress was also congruent for the participants and the literature. The participants frequently discussed a lack of focus on the caregiver from medical professionals, and mentioned instances of oversight that, while adding to the considerable stress experienced by the caregivers, was not addressed by medical professionals. As a result, participants discussed and demonstrated high levels of anger, guilt, impatience, chronic stress, anticipatory bereavement, and loss of self as they managed internal and external expectations and worked to protect the care recipient (Limardi et. al, 2015; Parks & Pilisuk, 1991; Bevans & Sternberg, 2012; Sautter et al., 2014).

The results from this study are also congruent with the protective factors of resilience to varying degrees. For one participant, her work as a spousal caregiver allowed her to find joy, experience gratitude, and relieve stress by focusing on positive experiences within caregiving (Olsen, 2003). However, the other participants mentioned few moments of joy that are directly related to their experiences as caregivers. As a whole, each participant did demonstrate reduced stress levels and fatigue through the use of positive coping techniques, help seeking behaviors, and social support, but the availability of these options varied greatly between participants (Clark, 2002). From this information, it is clear that existing literature on caregiver resilience does not include a wide variety of caregiving situations and does not include the desires and goals of the caregivers. As a result, more research is needed to determine the nature of how resilience relates to caregiving.

Available literature also discusses recommended measures that can be taken in order to mitigate the negative effects and provide respite for caregivers. These recommendations include educating the caregiver on the care recipient's disease through trainings and counseling practices, each with a focus on encouraging caregivers to improve their self-care practices and maintain their health (Aldeman et al., 2014). Though valuable, these recommendations ignore the scope of caregiving and the existing efforts caregivers are giving to both their work as caregivers and to maintaining themselves as individuals. In this study, each caregiver explicitly expressed a desire to better manage their health and self-care practices, but was restricted by the reality of their situation. As practitioners, it is critical that the caregiver's experience and reality is being considered when delivering recommendations in order to recognize the efforts the caregiver is already making, and how their desires fit with the available evidence. One clear example of this from the data is the poor implementation of the home health care program for Participant 1. In

this instance, the caregiver had been linked to these services but was incredibly dissatisfied with the quality of the respite help. This example demonstrates a critical need to continue to monitor respite services and to engage the caregiver in a discussion about the functionality and efficacy of the respite services they have been linked to. It is not enough that caregivers are given referrals, because, as shown in this study, often these referrals and resources are not meeting the needs of the caregivers. In future practice, caregivers should be monitored to ensure that the care desired is the care that is received from social service referrals and supports.

There is still a considerable need to involve caregivers in the care process by completing caregiver assessments and providing structured interventions. Through the interviews, the participants consistently discussed the lack of involvement by medical professionals in providing assessment, inclusion, and linkages to social support services or external resources. This lack of involvement is congruent with the available literature, which discusses the ways in which caregivers can receive support through home-based supportive services, community centers and community-based programs, and counseling options (National Academies of Sciences, 2016). Without ample and accurate referrals to social services, caregivers will continue to experience the negative effects of caregiver burnout, stress, and fatigue.

Despite the strong connections between the results of this study and the available literature on the caregiver experience, there are some limitations. This study looked at the experiences of only three caregivers. These caregivers were largely homogeneous in race, ethnicity, religion, age, and caregiving experience as familial caregivers, as each caregiver was providing care for someone with cancer. As a result, these findings may not be applicable to other caregiving experiences, despite the overarching and agreeing themes between each caregiver's story and variations in socioeconomic status and employment status. Additionally, this study did not draw

conclusive results on the impact of faith practices on caregiver resilience and experience, and did not sufficiently examine the degree to which the financial burden of caregiving impacts the caregiver experience. To decrease these limitations, further research should examine the extent to which the results from this study are applicable to additional caregivers, and should seek to answer how faith-based practices impact the caregiver.

Several recommendations can be gained from the data in this study. The first recommendation is to create a definition of resilience that reflects the perceptions of caregivers, rather than the perceptions of outside researchers. By creating a definition of resilience that reflects the population being defined, further research can examine the importance and connection of perception on resilience. A second recommendation is to increase and advocate for improved support and respite services. Because available literature did not reflect the extent to which the burden of caregiving impacted these participants, it is critical that further research specifically examines the impact of caregiver burden on caregivers in complex, chronic care situations. Without further research, there will continue to be inaccurate research on the extent to which complex, chronic caregivers experience caregiver burden. This inaccuracy prevents practitioners from decreasing the gap between caregivers' reality and desires in relation to support, respite aid, and management of external responsibilities.

Additionally, future advocacy and research on caregivers in complex, chronic care situations should focus on increasing recognition for caregivers within the medical field. Advocacy efforts need to work towards increasing physician interaction with caregivers in order to reduce oversight and exclusionary practices. Through this advocacy, caregiver guilt, impatience, stress, and anger can be addressed and managed to preserve the caregiver's sense of self and develop a positive balance between internal and external expectations. Additionally,

further research needs to specifically examine the impact of resilience as a mitigating factor on negative caregiver outcomes, and how the realities of caregivers impact their ability to utilize positive coping techniques, help seeking behaviors, and social support. Without accurate research on caregiver resilience in a variety of caregiving situations, it is not possible to clearly determine the nature of how resilience relates to caregiving. The final recommendation is to increase programming and educational services based on the actual needs and realities of caregivers, instead of what practitioners assume about caregiver needs. This is perhaps the most important recommendation, because without programs and services that represent the realities caregivers face, these programs will continue to inaccurately aid caregivers. Furthermore, once caregivers are referred to services and programs, it is critical that social service and healthcare practitioners continue to monitor the outcomes of these referrals in order to ensure the needs of caregivers are being met. Through increased oversight and improved programming and services, caregivers will be able to receive the respite aid they explicitly desired throughout this study. By following these recommendations in research, policy, and advocacy efforts, the desires of caregivers can become closer to their reality, and caregivers in complex, chronic care situations will see improved biopsychosocial outcomes throughout their time as a caregiver.

Caregivers are a critical and central component to healthcare within the United States, but despite this prevalence are frequently left out of both research and the treatment process. As a result, general support systems, research, policies, and practice methods must become more caregiver-centered, and the voices and experiences of caregivers should continue to be examined. This study creates a foundation for research that focuses on the caregiver experience with resilience and should continue to be utilized in further research to provide caregivers with a voice within their own lives.

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Appendices

Appendix A: Table 1. Identified Themes

Resilience – <i>(Caregivers behaved in this way, but did not see themselves in this way)</i> Strength; Faith; A person who keeps going in the face of adversity, bounces back from troubles, accepts reality and moves on		
Caregiver and Care Recipient Relationship and Disease	Caregiver as an Individual	Caregiver's Relationship with Others
<ul style="list-style-type: none"> • “[Understanding the terminal nature of his cancer] was a big burden on me for a long time until we finally came to terms with the fact [he] wasn’t going to be [ok] – it took him time.” • “Sometimes I feel like he’s draining every bit of life out of me” 	Reality: “I’m exhausted all the time” “Sometimes I feel like I’m going crazy” “I get very depressed”	Reality: “[In the beginning] I thought that we were all gonna be in it together...It didn’t turn out that way... That disappoints me.”
	Desire: “I can take a bath. Oh, my God I’m dying for a big bubble bath... I’ve taken showers for years... I miss my baths”	Desire: “If we could have an in-home nurse... taking care of [the house]. Just to have him be my husband and not [a] patient”

Appendix B

Interview Guide

- 1) Tell me about how you came to be a caregiver
- 2) When you are providing complex, chronic care, what does your typical day look like?

Complex, chronic care includes performing medical tasks (changing bandages, wound care, ect.), administering medication, and operating medical equipment
 - a. Tell me about your typical day as a caregiver.
 - b. What is the nature of others' help in caring for [insert care recipient's name]?
- 3) How do you define resilience?
- 4) What do you think contributes to your resilience?
- 5) What do you find to be the most challenging aspect of providing complex, chronic care?
 - a. How do you handle these challenges?
- 6) Tell me about the support, if any, you personally receive as a caregiver.
 - a. What would make you feel more supported?
- 7) How do you relieve tension and stress?
- 8) Is there anything else you would like people to know about being a primary caregiver?

Appendix C: Participant and Support Contact Email

Hello,

My name is Katie Simpson and I am an honors student at the Ohio State University in the College of social work. As part of my program, I am conducting a study that will create a better understanding as to how the primary caregiver for an individual diagnosed with cancer with complex, chronic care needs develops resilience. This study will focus on individuals who are currently caring for a loved one, and will examine how each individual defines resilience, their personal experiences regarding caregiving, and the caregiver's beliefs regarding their personal resilience. Each individual will be asked to participate in a single, in-depth interview lasting approximately one hour to 90 minutes, though there will be potential for follow-up clarification later in the study. I will meet the caregivers at a time a location that is most convenient for her or him. Participants will be given the utmost respect and all of the information shared with me will be kept private and confidential. Only my advisory, Dr. Holly Dabelko-Schoeny, will have access to the information.

For many in the United States, cancer has become a regular facet of life for many. As a high school student, my family faced cancer as my mother struggled with breast cancer for several years. Throughout this time, both my mother and father sought support through group settings, and the support was always more focused on the patient than the caregiver. Though this focus on the patient is necessary and vital to the healing process, it often overlooks the hardships faced by the caregiver as so much of the medical burden has become home-based. The stress faced by caregivers, and the resilience many develop as a necessary protection to the difficulties of cancer caregiving, I need participants who are willing to share their stories in order to create information to support the development of caregiver aid. Without the stories of current caregivers, it will not be possible to create a larger understanding of caregiver resilience and to further research into developing resilience in future caregivers. As a result of the overwhelming need to further research and support for caregivers, I am asking to work with your caregiver support groups to find individuals willing to be part of this research.

As a thank you for your participation, each participant will receive a \$25 Visa gift card prior to the start of the initial interview. Additionally, any participants selected for the member-checking process following the initial interview will receive an additional \$25 Visa gift card. These gift cards will be given at the time of the interview, and are not dependent on the completion of the interview process.

Please contact me to become involved and have your voices heard! I can be reached through email at simpson.572@osu.edu, over telephone at 614-753-7277, or through mail at the following address:

3101 Mt. Holyoke Road
Columbus, Ohio
43221

Thank you so much for your consideration

Appendix D: Consent Form

The Ohio State University Consent to Participate in Research

Study Title: The Development of Caregiver Resilience in Complex, Chronic Care Situations

Researcher: Katie Simpson, Holly Dabelko-Schoeny

Sponsor: The Ohio State University College of Social Work

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose:

The purpose of the study is to develop an understanding of how caregivers who provide complex, chronic care as the primary caregiver develop individual resilience by examining how caregivers define resilience, their personal experiences regarding caregiving, and caregiver's beliefs regarding their personal resilience.

Procedures/Tasks:

This study will comprise of an in-person interview for the duration of 1 to 1.5 hours, and will ask information regarding participant experiences in caregiving. The interview will be conducted in a secure location chosen by the participant, and will be recorded through handwritten notes and recording equipment. Following the initial interview, one participant will be selected for member checking, and every participant may be contacted for follow-up information over the telephone or in-person.

Duration:

You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits:

The process of discussing caregiving and resilience may ask participants to discuss difficult memories or traumatic moments. In order to reduce the risk of trauma, participants have the right to pass on any question and may withdraw from the study at any time without penalization. Additionally, researchers will uphold the highest level of cultural competence and will remain sensitive to participant reactions during the interview process.

The benefit from this study is the potential to expand information surrounding the process of developing individual caregiver resilience, which will inform future research and build upon the evidence base. Through the development of the available research, support for caregivers may be improved.

Confidentiality:

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:

Each participant will receive a \$25 Visa gift card immediately prior to the interview. An additional \$25 Visa gift card will be given to the participant that is chosen to complete the member checking process. These incentives are not dependent on the completion of the interview.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study, or you feel you have been harmed as a result of study participation, you may contact Katie Simpson at 614-753-7277, or Dr. Holly Dabelko-Schoeny at 614-292-4378.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

_____ Printed name of subject	_____ Signature of subject
	_____ Date and time
	AM/PM
_____ Printed name of person authorized to consent for subject (when applicable)	_____ Signature of person authorized to consent for subject (when applicable)
	_____ Date and time
	AM/PM
_____ Relationship to the subject	

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

**Printed name of person obtaining
consent**

Signature of person obtaining consent

AM/PM

Date and time

Appendix E: Cancer Support Community Support Letter

January 13, 2017

Katie Simpson

The Development of Caregiver Resilience

The Ohio State University

3101 Mt. Holyoke Road

Columbus, Ohio 43221

Dear Review Committee:

I am happy to provide the opportunity for Katie Simpson, an Ohio State University Honors Student in the College of Social Work, and her Advisor, Dr. Holly Dabelko-Schoeny, to recruit individuals from Cancer Support Community Central Ohio. I fully support the goal of this study as the research seeks to develop further understanding into the development of caregiver resilience in complex, chronic care situations.

I will provide access to individual caregiver participants at Cancer Support Community Central Ohio for in-person recruitment. I understand that the study will include voluntary, in-person interviews lasting approximately one hour to 90 minutes and potential, brief follow-up conversations for clarification. I understand the information shared by caregivers will be kept private and confidential, and participants will receive a \$25 Visa gift card as a token of appreciation.

Although support is available for caregivers in complex, chronic care situations, the research regarding the development and potential of caregiver resilience is lacking, which may lead to a lack of support for, and understanding of caregivers. Because this study seeks to understand the stories of individual caregivers as they define and express resilience, the information gathered has the potential to influence further research and theories surrounding caregiving and the development of resilience, which is critical to helping family caregivers in the future.

Sincerely,

Angie Santangelo, MSW, LISW-S

Clinical Program Director

Appendix F: Mount Carmel Support Letter



MOUNT CARMEL

Community Health Resource Center

777 West State Street, Room 119 • Columbus, Ohio 43222-1536

mountcarmelhealth.com

September 19, 2016

Re Katie Simpson
The Development of Caregiver Resilience
The Ohio State University
3101 Mt. Holyoke Road
Columbus, Ohio
43221

Dear Review Committee

I am happy to provide the opportunity for Katie Simpson, an Ohio State University Honors Student in the College of Social Work, and her Advisor, Dr. Holly Dabelko-Schoeny, to recruit individuals from Mount Carmel. I fully support the goal of this study as the research seeks to develop further understanding into the development of caregiver resilience in complex, chronic care situations.

I will provide access to individual caregivers at Mount Carmel for in-person recruitment. I understand that the study will include voluntary, in-person interviews lasting approximately one hour to 90 minutes and potential, brief follow-up conversations for clarification. I understand the information shared by caregivers will be kept private and confidential, and participants will receive a \$25 Visa gift card as a token of appreciation.

Though support is available for caregivers in complex, chronic care situations, the research regarding the development and potential of caregiver resilience is lacking, which may lead to a lack of support for, and understanding of caregivers. Because this study seeks to understand the stories of individual caregivers as they define and express resilience, the information gathered has the potential to influence further research and theories surrounding caregiving and the development of resilience, which is critical to helping family caregivers in the future.

Sincerely,

Brooke R. Benack MSW, LISW-S
Oncology Social Worker
Mount Carmel Health System
Columbus, Ohio
P: 614-234-1371
bbenack@mchs.com

RESPECT, COMPASSION, EXCELLENCE, CARE OF THE POOR AND UNDERSERVED, SOCIAL JUSTICE

